

# Ethics in Environmental Health

When it comes to the ethics of health research, “there’s been a presumption that ethicists and ethics committees will be in charge and solve ethical problems,” says Ann Cook, director of the National Rural Bioethics Project at the University of Montana in Missoula. More and more, however, environmental health researchers are realizing their need to be directly involved in the ethics questions facing them and their community partners.

Cook describes ethics as “something that everyone in the community has a stake in and needs to know about.” The NIEHS and the National Human Genome Research Institute agree. In 2002 the two institutes launched a grants program called Partnerships to Address Ethical Challenges in Environmental Health, which aims to tackle these issues by promoting community–researcher collaborations.

As part of the larger NIEHS Environmental Justice Program framework, the Partnerships program seeks to remedy the unequal burden borne by socioeconomically disadvantaged persons in terms of residential exposure to greater-than-acceptable levels of environmental pollution, occupational exposure to hazardous substances, and fewer civic benefits such as sewage and water treatment. Chief among ethical concerns for such populations is ensuring that research studies are designed and conducted with the involvement of those being studied rather than regarding them simply as study subjects.

Program grantees, including Cook’s team, receive up to \$200,000 annually for five years to investigate environmental ills in a community, survey residents’ attitudes about both local environmental problems and health studies in general, and develop educational campaigns to meet local needs. Grantee teams must include an environmental health scientist, a social scientist or expert on issues such as racial, ethnic, or socioeconomic discrimination, and a representative from a local community organization that works on environmental issues.

A variety of groups, from environmental organizations to schools of public health, receive funding through the Partnerships program. Grantees are now halfway through their projects and ready to discuss some of their findings—and frustrations.

## Defining “Community”

In an effort to develop a series of models for carrying out effective community review of environmental health research, Peggy Shephard, executive director of West Harlem Environmental Action (WE ACT) in New York City, and her colleagues have been listening in on NIH panel discussions between researchers and their community partners. Shephard’s team has also conducted a series of interviews and focus groups with environmental health researchers and their long-term community partners about the workings of such relationships.

One of WE ACT’s preliminary findings is that “we need to stop using the word ‘community,’” says Shephard. The word is repeated so often and in so many contexts that it’s becoming meaningless, she says. In part because “community” has no clear definition among researchers, “we’re coming to the viewpoint that there is never real ‘community consent’ for research,” she says. For example, she asks, is consent achieved when one community group okays a health study, or only when representatives of multiple community groups endorse it? WE ACT is addressing these and other questions—including how to appropriately define “community”—in an upcoming report.

## Ensuring Savvy Study Participants

Researchers at Boston University have rounded up four potentially divergent groups—public health officials, community activists, community residents, and representatives of academe—with the goal of coming to some common understanding of what is involved when scientists embark on a community health study. The team is led by David Ozonoff, an environmental epidemiologist at the Boston University School of Public Health.

What motivated the project, explains project manager and Ozonoff graduate student Madeleine Scammell, is the many calls to university and state health departments across the country from residents

concerned about a variety of potential health hazards in their towns. Callers often request a health study, yet when studies are done, communities are often unhappy with the results because of vastly differing expectations about what a health study provides, says Ozonoff. For example, researchers, perhaps preoccupied with the problem of statistical power for small populations, are often stricter than a lay person might expect as to what constitutes positive evidence of an environmental health problem.

At focus groups and during interviews that Ozonoff’s team conducted, residents often reported that it’s tangible evidence of pollution (such as soot on the cars) rather than media coverage that motivates them to take action, says Scammell. Community members are also more concerned than researchers may appreciate about research politics, such as why their town was selected as a study site.

## Teasing Out Interactions

A 200-mile stretch of New York’s Hudson River has achieved the dubious distinction of being one of the country’s largest Superfund sites. Staff at the W. Haywood Burns Environmental Education Center in Albany, where the Hudson and other polluted waterways converge, are investigating what this distinction means for residents of Albany’s poorest neighborhoods.

Led by principal investigator Donna Perry, a registered nurse at the Burns Center, the team and their community partners interviewed residents in 80 primarily African American households to get baseline information on respondents’ health and environment. They found that half of the respondents were smokers. Many had been physically assaulted and reported frequently hearing gunshots near their homes. The smell of gasoline, sewage, and exhaust also was common near their homes. Almost 44% of respondents had breathing problems. Perry and her colleagues are now determining whether the exposure to environmental pollutants in combination with smoking, emotional stress, heredity, lifestyle, and even community zoning decisions may create significant health hazards.

The team is developing health and environmental education materials that are culturally sensitive to the Albany residents they serve. Recommendations for conducting environmental health surveys in urban communities and communities of color are forthcoming, says Perry.



## Countering a Toxic Talisman

Downriver from Albany, Hal Strelnick, a physician at Montefiore Medical Center in the Bronx, leads the South Bronx Environmental Justice Partnership. He and his colleagues are focusing some of their ethics grant dollars on an unusual problem with mercury: members of various religious groups believe that spreading this toxicant around their homes will bring good luck and ward off evil, explains Strelnick.

The ethical challenge of establishing rapport and trust with these groups is complicated; when the New York City Department of Health banned the sale of elemental mercury at the folk pharmacies serving some of these groups, adherents became reluctant to discuss the practice with outsiders. "We wanted to determine if there was a more productive and respectful and ethical way [to educate about mercury]," Strelnick says.

South Bronx residents are not "aware of mercury as an environmental problem unto itself, though they are highly aware of lead, and they understand when you explain that mercury acts like lead in the body," says Strelnick. The team is partnering with community religious leaders to develop a protocol for educating the public, without panicking them, about the dangers of the ritual use of toxic substances. They are also working on a more general public information campaign on how residents can assess and address community environmental issues.

## Building Trust and Community Capacity for Research

If you ask representatives of community organizations in an area neighboring a prestigious medical school about environmental health and community-researcher relations, you'd better be prepared for a landslide of ideas on how to build effective partnerships. That's what Mark Farfel, a public health researcher at the Johns Hopkins Bloomberg School of Public Health in Baltimore, Maryland, and colleagues discovered when their Environmental Justice Partnership sought feedback about how to improve the research process.

The partnership uses a participatory model and comprises staff and faculty at the Bloomberg School of Public Health, 11 different East Baltimore organizations, and faculty and students from the Maryland Institute College of Art.



Focus group participants spoke about the poor state of their community's environment and described negative experiences during research studies, including lack of communication from researchers conducting studies and lack of community involvement. Participants were not entirely negative, however. They agreed that research can be beneficial if the community is involved up front, if the findings are shared with participants and the community at large, and if community-researcher partnerships work to sustain needed programs and policies.

The partnership has followed up by writing grants with board organizations, holding a community fair, and designing educational programs for residents about issues such as lead poisoning. The community board is also working with the Bloomberg School of Public Health to ensure that research in East Baltimore is mutually beneficial.

## Putting Environmental Research on Stage

Communities in North Carolina face environmental contamination from multiple sources, from hog slaughterhouses to wood-laminating industries. Carolyn Crump, a public health scientist at the University of North Carolina at Chapel Hill, and her community colleagues are using theater, along with more traditional educational materials, to open discussion on how health research affects the people who live near pollution hot spots. The team is writing and piloting scripts in the style of Reader's Theater, in which performers read from a script rather than act out memorized parts. They are also developing facilitator guides that will identify key points for discussion following the performances.

The theater pieces may be performed at community centers, schools, churches, government or other professional offices, conferences, and workshops. The performances are meant to encourage performers and audience members to talk about, among other topics, their understanding of the role of research in identifying environmental hazards, says Crump.

The performances will also document the stories of communities fighting for environmental justice and the experiences of attorneys and researchers who work on environmental health issues. "Cross-disciplinary exchange is one of the main [intended] outcomes of our project," Crump says.



## Mining the Community Goodwill

Cook's team in Montana is working with residents in Libby, a mining town in the upper northwest corner of the state. A vermiculite mine that operated in Libby from 1921 to 1990 exposed workers, their families, and the local environment to dangerous levels of toxic amphibole asbestos. "When you are dealing with Superfund kind of issues, communities can get fractured, so we are using information and ethics to bring people together," says Cook.

Earlier health studies have shown that scientists, health care providers, and Libby residents alike need more information on many issues related to asbestos, including the health risks and health care options. To meet that need, Cook's team is offering a website (<http://www.umt.edu/Libbyhealth/>) where visitors can read facts that dispel myths about asbestos, download learning activities, and read summaries written in lay language of the legal and scientific issues involved in the Libby case.

The team is also field-testing material designed to help people with asbestos-related disease and other community members understand what a research project is. "In places such as Libby, where there is lots of research going on, you need to clarify what it means to participate in a research project," says Cook.

To reach out to younger members of the community, the group is developing materials on asbestos and the history of the community for use in local schools. "Schools didn't discuss [the asbestos problem] with students because it was perceived as a hard topic to talk about," Cook says.

## Training International Bioethicists

The need for better partnerships between communities and researchers is in no way unique to the United States. The NIEHS also cosponsors, along with several other NIH institutes, projects that address inequities in developing countries.

Developing countries present unique bioethical challenges, says bioethicist Ruth Macklin of the Albert Einstein College of Medicine in the Bronx. For one thing, in countries where many participants are illiterate, written informed



consent documents are inappropriate. In addition, she says, the lack of well-trained institutional review boards makes independent ethical review almost impossible. There is also pointed debate about whether foreign investigators need to provide care that is better than or equivalent to what the study participants would normally receive in their country.

To address such issues, Macklin and her colleagues provide seven months of bioethics training every year in Buenos Aires to four Latin American professionals and scholars with experience in studies involving human subjects or research ethics. The training is funded by the John E. Fogarty International Center's International Bioethics Education and Career Development Awards program, which gives foreign and domestic universities up to \$250,000 annually to support international bioethics education for professionals from low- and middle-income countries.

Under the guidance of Macklin and her colleagues, participants take courses in bioethics, attend meetings of different research ethics committees, and prepare a detailed plan for implementing activities in research ethics at their home institutions.

Macklin's recent graduates "are almost without exception engaged in ongoing research or program development in bioethics," she says.

### A Group Effort

When academic and community groups work together, whether in the United States or abroad, collaborators and participants need to address their long-held assumptions about science, communities, and poverty, ethics grantees say. For example, says Farfel, some African Americans are wary of researchers and their studies in the wake of the infamous Tuskegee Syphilis Study conducted from 1932 to 1972, during which the Public Health Service denied treatment to almost 400 poor African American men who had the disease. Episodes like that lead many would-be study participants to view research as something done *to* them, not *for* them, Farfel says.

Nevertheless, residents are increasingly receptive to this approach of bringing ethics and community participation into all aspects of environmental health research. "Receptive, yes," says Cook. "And cautious." —**Tina Adler**



## Symposium Explores Children's Environments

"When we try to pick out anything by itself, we find it hitched to everything else in the Universe." Quoting naturalist John Muir, Michael Fischer, an environmental consultant formerly of the William and Flora Hewlett Foundation, introduced the 2004 Biennial Scientific Symposium on Children's Health as Impacted by Environmental Contaminants by emphasizing that



## Schwartz Named New NIEHS/NTP Director

On 25 October 2004 NIH director Elias Zerhouni announced the appointment of David Schwartz as the new director of the NIEHS and the National Toxicology Program. Schwartz, who will assume his new duties on 4 April 2005, is currently director of the Pulmonary, Allergy, and Critical Care Division and vice chair of research in the Department of Medicine at Duke University. While at Duke, Schwartz has also played a leading role in developing interdisciplinary Centers in Environmental Health Sciences, Environmental Genomics, and Environmental Asthma. Schwartz's research has focused on the genetic and biological determinants of environmental lung disease and host defense.

Schwartz is filling the position left open by Kenneth Olden, who stepped down from the post late in 2003, but who agreed to remain in the position until his successor was named. Olden will stay on at the NIEHS as a researcher in the intramural program.

At the announcement of the appointment, DHHS secretary Tommy Thompson called Schwartz "one of the nation's outstanding researchers in environmental health." Thompson and Zerhouni acknowledged the leadership role that Schwartz is taking on at the NIEHS as environmental factors are being implicated more often in the etiology of disease. Zerhouni touted Schwartz's interdisciplinary approach as one that "will help lead us to well-conceived strategies for preventing, diagnosing, and treating disease."

As director of the NIEHS, Schwartz will oversee a \$711 million budget that funds multidisciplinary biomedical research programs, as well as prevention and intervention efforts that encompass training, education, technology transfer, and community outreach. The NIEHS currently supports more than 850 research grants.

"I am delighted and honored to join NIH," said Schwartz. "My vision for NIEHS is to improve human health by supporting integrated research and career development in environmental sciences, environmental medicine, and environmental public health. Given recent advances in biomedical research and computational biology, NIEHS is well positioned to use its expertise in toxicology to understand human biology, disease pathogenesis, and the unique distribution of disease in different populations."

children are at the nexus of many of the connections found in nature.

The symposium was designed to explore the interconnectedness of all elements of the environments in which children live, learn, and play, as well as ways to prevent environmental health risks. Hosted by the Children's Environmental Health Institute (CEHI), the symposium was held 24–25 September 2004 at the McKinney Roughs Nature Park in Austin, Texas. The symposium was sponsored by the NIEHS, Physicians for Social Responsibility, the Texas Medical Association, the Lower Colorado River Authority, and the Centers for Disease Control and Prevention. The interdisciplinary group of participants included researchers, pediatricians and other health professionals, social workers, nonprofit and advocacy group representatives, architects, and engineers.

Topics ranged from the cellular level to the global. Because environmental toxicants are ubiquitous in air, water, food, and medications, said pediatrician and speaker Martin Lorin, we have seen a global rise in environmentally related diseases. However, in terms of the extent of the effects of exposures, he contended, we are seeing only the tip of the iceberg.

Participants agreed that to reduce harmful immediate and long-term effects of contaminants on children, we must study the interactions of environment, genes, developmental stage, and behavior. Discussions on endocrine disruptors (by John McLachlan of Tulane and Xavier Universities), developmental defects (by Richard Finnell of Texas A&M University), and respiratory disease (by Sharon Petronella of The University of Texas Medical Branch, Galveston), for example, addressed not just specific immediate health problems in children but also future trends: What kinds of adult diseases might be projected from fetal and childhood exposures? And how healthy are future populations likely to be?

Potential remedies for environmentally related health problems may be as simple as taking folic acid to help prevent birth defects or having a physician take an environmental history to spot potential health risks. Technical (air quality samplers, handheld immunosensors, microarrays) and demographic (geographic information systems, longitudinal studies) tools also can help identify and alleviate environmental health threats.

The built environment—both materials and design—can significantly reduce children's exposures to toxicants while creating safe and stimulating places to grow and learn. How do we replace the persistent

## Headliners

NIEHS-Supported Research

## Respiratory Health



### Air Pollution Impairs Lung Development in Children

Gauderman WJ, Avol E, Gilliland F, Vora H, Thomas D, Berhane K, McConnell R, Kuenzli N, Lurmann F, Rappaport E, Margolis H, Bates D, Peters J. 2004. The effect of air pollution on lung development from 10 to 18 years of age. *N Engl J Med* 351(11):1057–1067.

Mounting evidence suggests that exposure to air pollution has long-term effects on lung development in children; reductions in lung function have been observed in studies in Europe and the United States. To further investigate these effects, this NIEHS-supported research team performed a prospective epidemiologic study on 1,759 children from 12 communities in Southern California.

The communities had a wide range of exposures to air pollutants including particulate matter, acid aerosols, ozone, and nitrogen dioxide. The team recruited fourth-graders and performed lung function tests annually for eight years.

Over the eight-year period, decreases in a measurement of lung function known as forced expiratory volume (FEV<sub>1</sub>) were associated with exposure to nitrogen dioxide, acid aerosols, particulate matter, and elemental carbon. The decreases noted were statistically and clinically significant. For example, the risk of diminished FEV<sub>1</sub> was almost five times higher at the highest level of particulate matter exposure than at the lowest level. The magnitude of the effects on development of lung function was comparable to that reported for exposure to maternal smoking.

The authors conclude that these results can be generalized to children living in other parts of the United States that have high air pollution levels. The results indicate that current ambient air pollution levels can have chronic and adverse effects on lung development in children, leading to clinically significant lung function deficits in adulthood. Given the severity of the effects and the importance of lung development as a determinant of morbidity and mortality during adulthood, it is important to continue identifying strategies for reducing air pollution. —Jerry Phelps

bioaccumulative and toxic chemicals used to produce building materials with less-toxic alternatives?

Gail Vittori, codirector of the Center for Maximum Potential Building Systems, suggested several methods, among them eliminating interior finish materials that offgas volatile organic compounds, using recycled fly ash as a substitute for concrete, labeling building products more thoroughly, and using paints certified by the independent Green Seal standards program.

Vittori also recommended that builders participate in the Leadership in Energy and Environmental Design program, a voluntary standard established by the U.S. Green Building Council for assessing and certifying high-performance sustainable buildings. In schools, inadequate ventilation, use of toxic pesticides and cleaners, offgassing from building materials and furnishings, and poor maintenance should be remediated to avoid increases in asthma, allergies, and other respiratory diseases.

With an eye toward the future, the NIEHS and the U.S. Environmental Protection Agency will continue to fund the Centers for Children's Environmental Health and Disease Prevention Research, according to NIEHS director Kenneth Olden. These centers promote multidisciplinary research and the translation and application of research to public health and clinical practice. The Centers for Disease Control and Prevention aims to expand environmental public health tracking to a full nationwide network, collecting and analyzing data on hazards, exposures, and health effects. And Fernando Guerra, director of health with the San Antonio Metropolitan Health District, noted that the multi-agency National Children's Study "will provide for the first time an opportunity for children and families to benefit from the cumulative evidence that will be assembled over twenty-five years, to better understand causal relationships from many different influences, including the environment."

The participants concluded that prevention, remediation, and attention to the long term are essential to addressing the unique vulnerabilities of infants and children. The challenge presented here is to blend research and clinical work with advocacy. Said CEHI director Janie Fields: "Together we are building a structure that bridges the health information gap between the medical, research, and environmental communities."  
—Martha M. Dimes

## Help Instead of Hype

Breast cancer strikes 1 in 7 American women, making it the most commonly diagnosed cancer among women in the United States. Although certain genetic factors can play a part in the etiology of the disease, scientists are studying other important factors including estrogen-related factors, lifestyle choices, and environmental risk. Understanding these factors can help women make informed decisions about their health and avoid being another breast cancer statistic.

Researchers at the NIEHS-funded Center for Environmental Health and Susceptibility, housed in the University of North Carolina at Chapel Hill School of Public Health, are leading the way in determining both the genetic and other causes of breast cancer. And the center's Community Outreach and Education Program (COEP), headed by Frances M. Lynn, a professor of environmental sciences and engineering, has developed a workshop program to spread the word to North Carolina residents that they need not be helpless victims of this disease.

To assist in developing the workshop, the COEP partnered with the Breast Cancer Coalition of North Carolina, a nonprofit organization that advocates on behalf of those with breast cancer and their families. A scientific advisory board representing a variety of medical disciplines reviewed the workshop materials and continues to work with COEP staff to answer participants' questions and keep the workshop as current as possible.

Visitors to the center's website can download the workshop materials at <http://www.sph.unc.edu/cehs/outreach/elsi.htm>. Visitors can download the 15-slide PowerPoint presentation that is used in the workshop, as well as an agenda, facilitator instructions, case studies, fact sheets, and take-home activities.

The presentation introduces the workshop audience to the known possible risk



factors for breast cancer, as well as some risk-reduction measures women can take. The presentation divides risk factors into four groups: personal or estrogen-related risk, lifestyle risk, environmental risk, and genetic or inherited risk.

The environmental risk portion of the presentation explains gene-environment interactions that occur as a result of exposure to toxicants and how that differs from risk associated with inheriting one of the so-called breast cancer genes (*BRCA1* or *BRCA2*). Despite the frightening prospect of breast cancer running in families, only 5–10% of breast cancer cases are thought to be genetic in origin. Slides describe instances where this inherited risk may be implicated in breast cancer. Participants also learn about the ethical, legal, and social implications of genetic testing—how the testing is done, how they should decide if they need it, and what may happen

if they test positive.

The interactive portion of the workshop includes fun learning activities, such as Reduce Breast Cancer Bingo, which has been a hit with the senior citizens that have taken part in the program to date. Participants win when they correctly identify four risk-reduction facts in a row, including the importance of exercising, eating vegetables, and limiting exposure to secondhand smoke. A related activity presents participants with fictional case studies for three women, one with a family history of breast cancer, one with lifestyle risk factors, and one with environmental risk factors. Participants are asked to identify both the risk factors and any protective factors each woman has, and to recommend how each woman might reduce her risk.

The workshop, which has been conducted across North Carolina, has been developed so that women who have completed it know not only how to better care for themselves but also how to advise other women. In conducting the workshops, COEP staff hope to dispel some of the myths women have about breast cancer and instill optimism instead. —Erin E. Dooley

